

# Mental health support case studies

## 2023-2024

### Improving mental health screening and signposting support pathways

#### Organisation

Isle of Wight NHS Trust

#### Project team:

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Dr Laura Bohane, Clinical Psychologist

#### Project aim

To design, test and implement a mental health screening process and signpost children and young people to a variety of mental health resources by May 2024.

#### Background/rationale

The Isle of Wight NHS Trust paediatric service team works within a small District General Hospital. It is unique in its locality and currently cares for a caseload of approximately 100 children and young people diagnosed with epilepsy, who are seen in general paediatric clinics by eight general paediatric consultants. While some complex patients are managed jointly by secondary and tertiary services, who have access to an epilepsy nurse, most children and young people rely solely on the local paediatric consultants for their care.

The team aims to improve the identified gaps in routine screening for mental health, behavioural, and developmental conditions, including the lack of consistent access to a psychologist. At present, the team does not engage in quality improvement activities and lacks regular patient and family engagement activities due to resource constraints and the absence of a dedicated epilepsy clinic and epilepsy specialist nurse. Although there is a children's community nursing service within the paediatric department, there is no dedicated community outreach team.

#### What was the problem?

National audit results reported in Epilepsy12 highlighted these known gaps. The project's focus is on improving an area that is achievable and measurable, resulting in meaningful change, without any additional funding or resources. Epilepsy12 audit results identified

mental health screening as a key area for service improvement. Additionally, many families had expressed a need for psychological support and were struggling to access this through community mental health services. Prior to joining EQIP, the team gained access to a small amount of paediatric clinical psychology time, which they plan to use effectively.

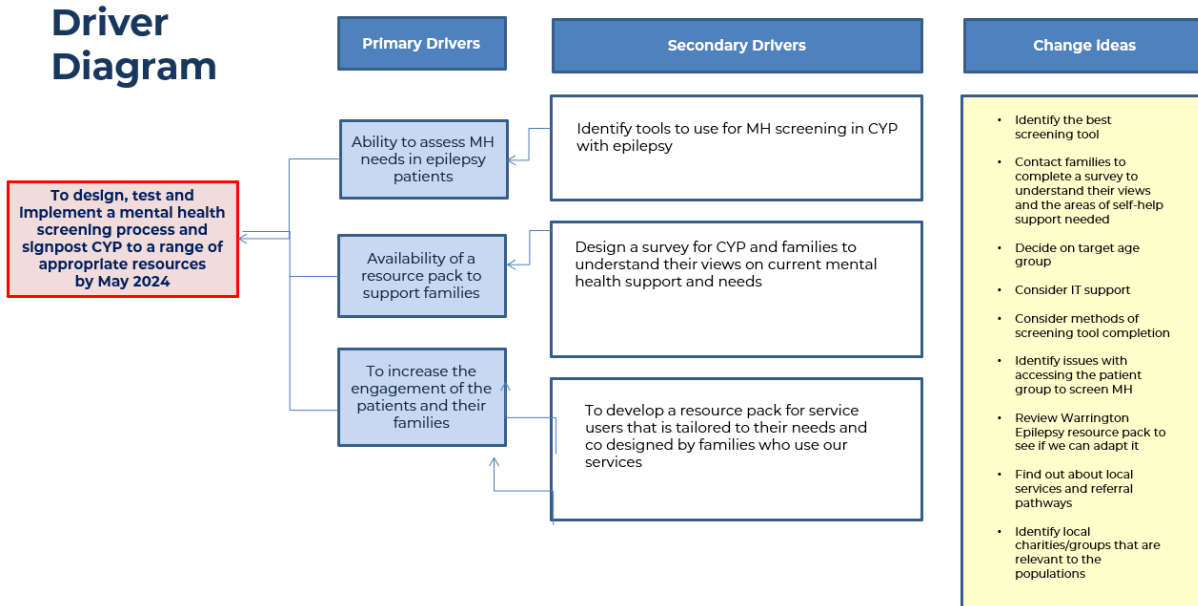


Figure 1: Team driver diagram that provides a clear statement of their project aim, with primary and secondary drivers that visually display the team’s theory of what “drives”, or contributes to, the achievement of a project aim.

## Stakeholder Map

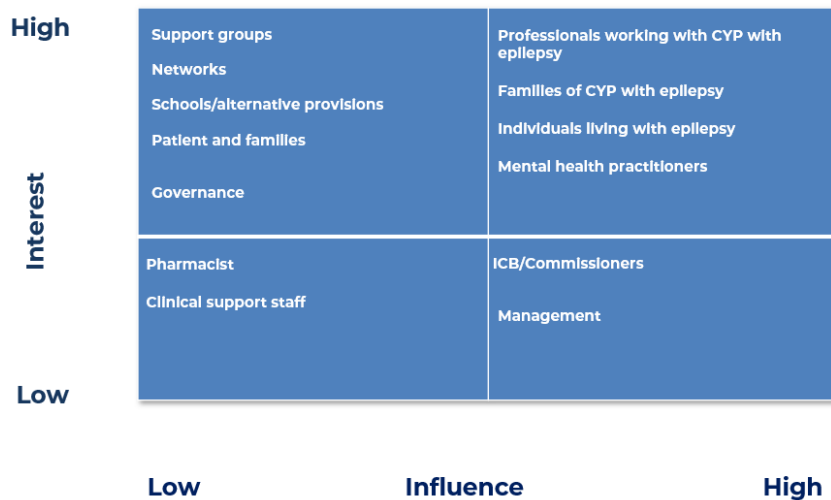
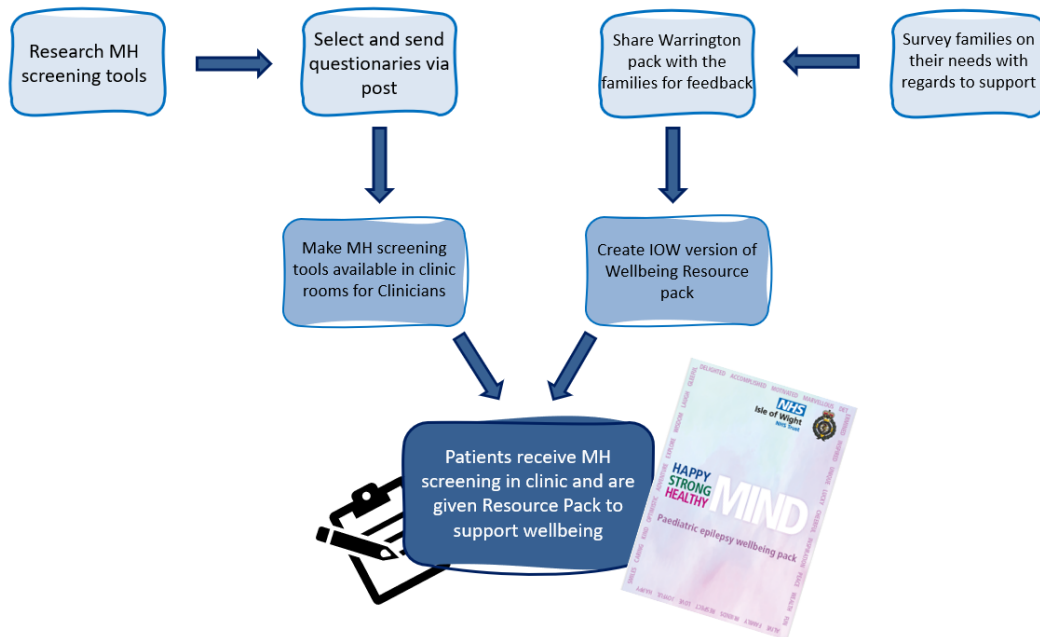


Figure 2: Shows the project stakeholder map, which provides analysis of stakeholders that are of influence/interest to the project. Stakeholders are plotted on the grid to guide the actions you should take for involving and communicating with them.

## What was the solution?

The team recognised the importance of providing comprehensive psychological and physical care for children and young people with epilepsy, adopting a combined approach to address both aspects. They emphasised the need for information and supportive resources for children, young people, and their families struggling with the diagnosis. The plan aimed to increase engagement with patients and families, involving them in designing resources that meet their needs.



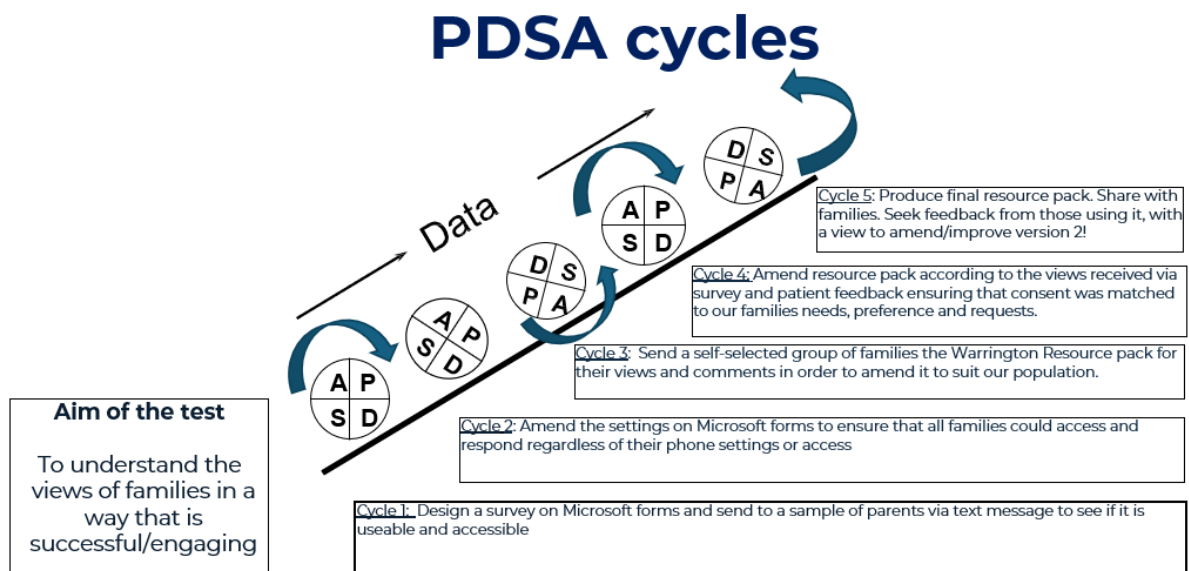
**Figure 3: Shows the team's project process map of their journey for improvement.**

The following actions were taken:

1. **Identify a suitable screening tool:** The team tested several mental health screening questionnaires with children, young people, and their families, to gain their views on the current level of care provided by their service and the usefulness of the screening questionnaire. The following mental health screening tools were tested with families:
  - a. [PedsQL \(Paediatric Quality of Life Inventory\) screening tool](#). The PedsQL Measurement Model is a modular approach to measuring health-related quality of life in healthy children and adolescents and those with acute and chronic health conditions.
  - b. [Revised Child Anxiety and Depression Scale \(RCADS\)](#) tool is a 47-item, youth self-report questionnaire with subscales including separation anxiety disorder, social phobia, generalized anxiety disorder, panic disorder, obsessive compulsive disorder, and low mood.

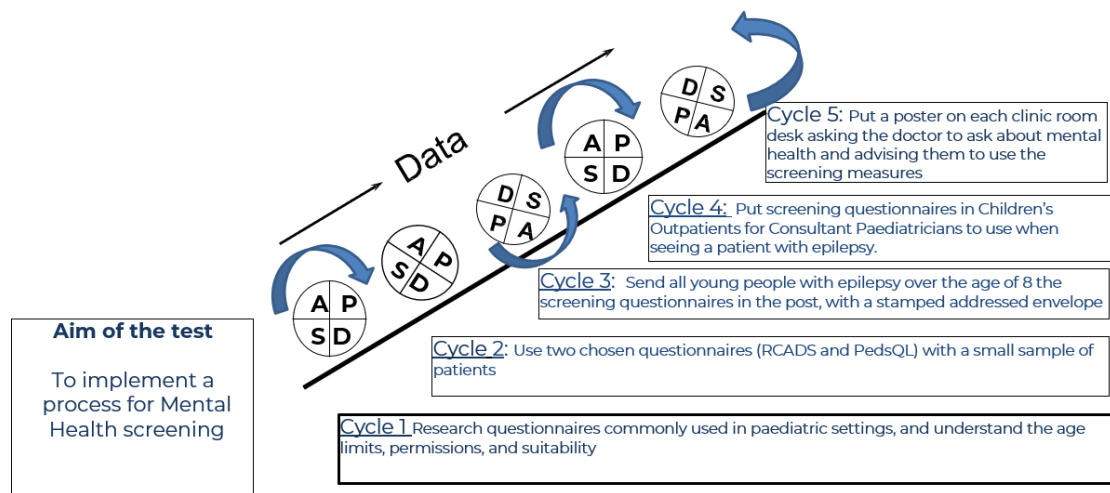
Selection: PedsQL was the preferred choice for its specificity to children and young people with epilepsy.

2. **Data collection:** The data collected from the mental health quality of life questionnaires were assessed and used for two purposes:
  - a. Individual level: Surveys and questionnaires helped identify individuals needing specific interventions to address their mental health needs or improve their quality of life.
  - b. Group level: The data provided an overall understanding of mental health needs and quality of life, identifying common trends or areas requiring further intervention.
  
3. **Testing and distribution:** Initial testing was conducted with a small group of children over the age of 8 years to refine the process prior to sharing the forms for wider distribution. In total, there were 66 families with children aged 8 years or over. Printed copies were available in outpatient clinics and distributed via the consultants.



**Figure 4: Shows the Plan, Do, Study, Act (PDSA) cycles of change ideas to engage with young people and families within the driver diagram being tested.**

## PDSA cycles



**Figure 5: Shows the PDSA cycles of change ideas for developing a mental health screening pathway within the driver diagram being tested.**

4. **Patient engagement:** Feedback surveys were designed and sent via text message to all families and QR code posters of the survey were displayed in clinics to include the views of children, young people, parents and carers on the standard of care received and suggestions for service improvements. Notice boards were used in children's outpatient departments to communicate the project, provide access to resources, and gather feedback.
5. **Resource pack development:** The team planned to adopt and implement a mental health and wellbeing resource pack developed by the EQIP Warrington and Halton hospital paediatric service team, tailoring it to their patient population. Families were invited to join a small group to co-produce changes to the resource pack. Five families agreed to review and provide feedback on the resource pack content.
6. **Local resources:** The team undertook local research to identify available resources and services that could be signposted to support children, young people and families such as a locally run epilepsy support café, which was added to the wellbeing pack. Minor adjustments to the order of content were implemented based on survey responses.

### What were the challenges?

The following challenges highlight the practical and logistical difficulties faced by the team in implementing their improvement project.

- **Age range decision:** The team initially planned to engage children and young people from the age of 10 years and over, which was changed to over the age of 8 years.
- **Technical issues:** The initial sample survey sent to three families had a non-functioning link, which required correcting.
- **Time constraints:** There was very limited time to work on the project.

- **Data management:** Gathering and analysing screening questionnaire data was time-consuming.
- **Physical space:** Lack of a dedicated epilepsy clinic and no dedicated epilepsy team made implementing changes to practice more difficult.
- **Consultant engagement:** The clinic is managed by eight consultants who treat children and young people with epilepsy but seven did not participate in the improvement programme. This complicated patient engagement due to infrequent appointments (every 4-6 months) which present challenges in securing their buy-in.
- **Lack of epilepsy specialist nurse:** No input from an epilepsy nurse creates a significant affect with patients' feeling unsupported and the effects on the standard of care delivered.
- **Infrequent appointments:** Insufficient time to capture feedback from patients and families due to the irregularity of clinic visits from patients that meet the criteria within the projects time frame.
- **Screening process:** Ideally, mental health screening tools would be administered in person to allow thorough exploration and generate conversation, but practical constraints resulted in sending them to families for self-completion.
- **Poor return rate:** Low return rate of screening questionnaires, which ideally should be completed in the clinic.
- **Scoring and action time:** Significant time is needed to score questionnaires and take action after completion.

## What were the results?

The mental health screening questionnaires and feedback forms were sent to 66 families with children over the age of 8 years via post. In total 27 families responded to the survey, seven responded with screening questionnaires and four families agreed to help develop some resources.

Feedback results were captured from children, young people and their families on the following:

- **Service improvements:**
  - Many families highlighted a lack of support for staying safe with epilepsy.
  - There was a significant need for support from local services, online epilepsy resources, and general epilepsy management.
  - Mental health feedback identified the need for support with low mood and anxiety management.
  - Qualitative data revealed issues such as the absence of an epilepsy nurse, lack of a contact point, geographic barriers, and insufficient mental health support.
- **Routine enquiries and resource access:**
  - Families reported that children's mental health was not routinely addressed.

- They also mentioned difficulties in finding resources to support their understanding of epilepsy and mental health.
- Families expressed the need for more mental health support but struggled to access it.
- Quick, accessible phone surveys were well received by families.

● **Patient and family needs:**

- Patients and families were not regularly asked about their mental health and wellbeing.
- There was uncertainty about where to find help and support.
- Families preferred face-to-face contact methods.
- There was significant interest in general epilepsy advice, with a particular focus on mental health, anxiety, and wellbeing.

● **Local context:**

- The Isle of Wight has a high percentage of children and families living in poverty.
- There is also a large proportion of children with special needs, autism, and ADHD.
- Resource information will be made inclusive and accessible to all families.

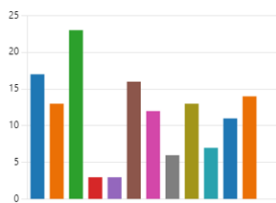
● **Resource pack feedback:**

- Families indicated they were randomly searching for resources, risking access to inaccurate information.
- A short survey asked families for their views on the resource pack, including what they liked, disliked, and what they would change about the content and layout.
- Five families agreed to review and provide feedback on the Warrington and Halton “Happy, strong, healthy Mind” wellbeing pack.

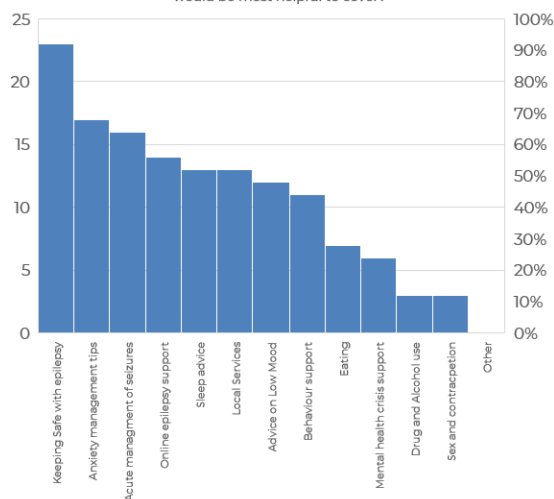
9. If we were to design some supportive resources, what topics do you think would be most helpful to cover?

[More Details](#)

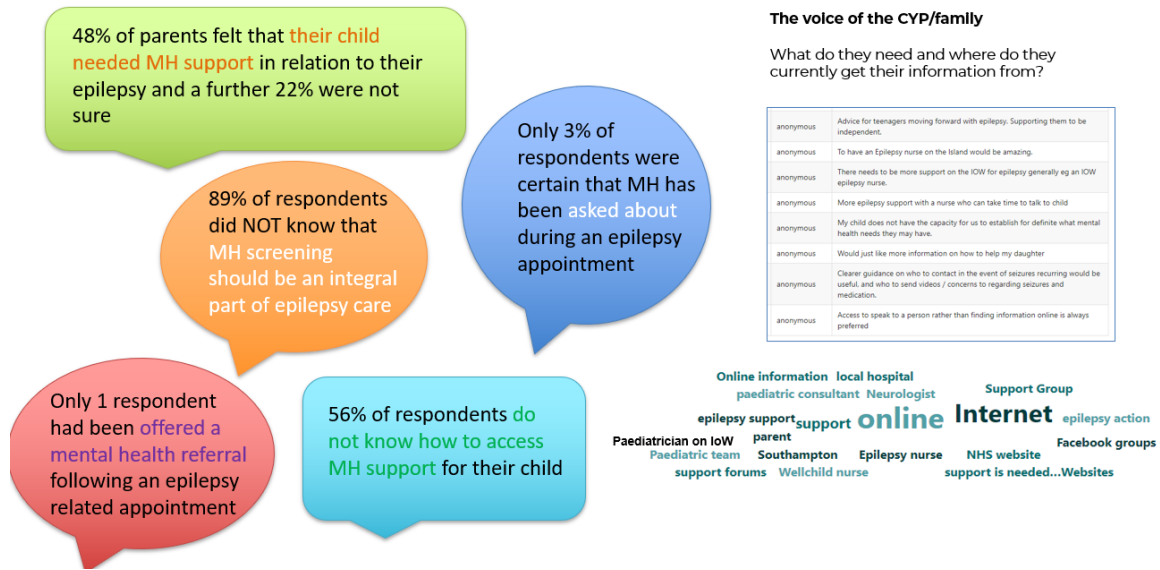
- Anxiety management tips 17
- Sleep advice 13
- Keeping safe with your epilepsy 23
- Drug and alcohol use 3
- Sex and contraception 3
- Acute management of seizures 16
- Advice on Low Mood 12
- Mental health crisis support 6
- Local services 13
- Eating 7
- Behaviour support 11
- Online epilepsy support 14
- Other 0



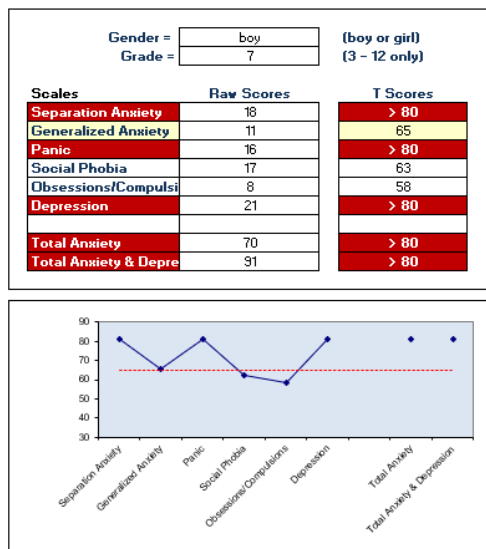
**Pareto chart - Survey Question 9**  
"If we were to design some supportive resources, what topics do you think would be most helpful to cover?"



**Figure 6: Pareto chart of patient and family feedback from mental health quality of life questionnaire.**



**Figure 7: Patient and family feedback from mental health quality of life questionnaire.**



	IMPACT	COGN. F.	SLEEP	EXEC. F	MOOD
<b>MAX SCORE</b>	<b>900</b>	<b>600</b>	<b>300</b>	<b>600</b>	<b>500</b>
1	350	25	75	225	500
2	25	0	25	0	N/A
3	200	175	0	150	250
4	550	25	100	250	275
5	0	0	0	0	0
6	500	175	125	0	300
7	376	50	0	75	225
8	600	175	50	0	75

**Figure 8 (left): RCADS is a 47-item youth self-report questionnaire with subscales. Posted to all children and young people with epilepsy over the age of 8 years. Seven responses, one of which was incomplete. Five of these met clinical threshold for self-reported anxiety disorder and/or low mood.**

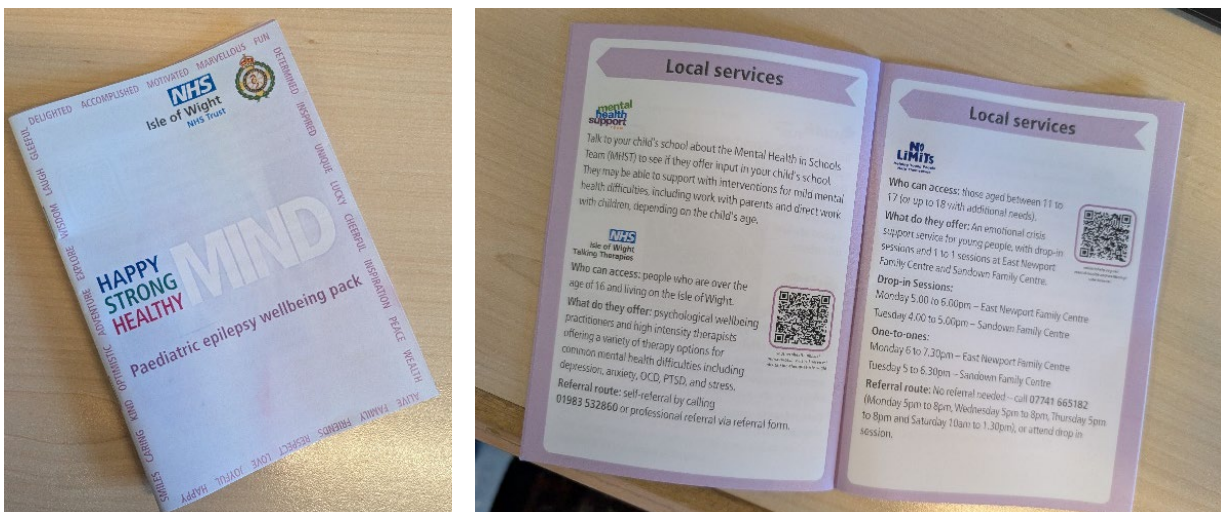
**Figure 9 (right): PedsQL – Epilepsy Module: Scored results.**

## What was the outcome?

- **Resource pack for families:** All children and young people and their families now have access to a co-produced resource pack with high-quality self-help materials and local and national signposting information.



- **Team Cohesion:** The project fostered a dedicated and enthusiastic team, uniting members with a shared goal.
- **Understanding mental health needs:** There is now a better understanding of the mental health needs of children and young people who attend their service.
- **Patient involvement:** The project has incorporated the voice of patients and families within improvement processes to support ongoing service development initiatives.
- **Equity of care:** Efforts have been made to reduce variation in patient experience, ensuring equity of care for all.
- **Increased awareness:** The team is now more aware of the need to ask about and screen for mental health difficulties in patients with epilepsy.
- **Screening process:** Screening tools are now available for use within the clinic setting to effectively screen for mental health conditions in children and young people with epilepsy.
- **Future plans for an epilepsy specialist nurse:** The voice of patients and families, captured through surveys, will be used to demonstrate the need for an epilepsy specialist nurse (ESN). Access to an ESN will help to create an even better pathway.
- **Continuous feedback and improvement:** There are plans to gather feedback on the resource pack to make further changes if needed, ensuring it continues to meet the needs of children and young people and their families.



**Figure 10: Images of Isle of Wight version of the Warrington and Halton “Happy, strong, healthy Mind” resource pack for families. The resource pack was reviewed and edited working with children and young people to ensure the content met with their needs.**

## What were the learning points?

- **Shared learning and preparation:** Being prepared to present findings at a clinical effectiveness meeting were crucial.
- **Ineffectiveness of postal method:** Sending the screening questionnaires by post to children, young people and their families proved ineffective due to postal costs and a very low return rate.

- **Engaging peers:** Clinicians need visual prompts incorporated into the process to remind them to use screening measures when seeing children and young people with epilepsy in clinic.
- **Importance of family voices:** Including the voice of children and young people and their families is vital for understanding their needs and involving them in the improvement process is crucial to service improvement.
- **Ineffectiveness of paper questionnaires:** Distributing paper questionnaires is not an effective engagement method and resulted in poor return rates.
- **Effective team collaboration:** The team worked extremely well together, using communication methods such as WhatsApp to keep all team members updated, because of the minimal opportunities to meet in person.
- **Optimising team skills:** Each team member's skill set was utilised to optimise productivity and move the project forward cohesively.
- **Engagement with key stakeholders:** Collaborating with the Integrated Care Board lead and Operational Delivery Network was essential for addressing the need for an epilepsy nurse and improving overall care.

### Next steps and sustainability

- Encourage all consultant paediatricians to ask about mental health during patient consultations and use screening questionnaires in clinics.
- Share the resource pack with all families.
- Refer children and young people with the highest support needs to a paediatric clinical psychologist for one-to-one consultation.
- Encourage self-referrals and make referrals to mental health services or third sector organisations when indicated.
- Create a business case for an epilepsy nurse specialist, using the feedback from parents gathered in the project survey.
- Continue to gather further patient feedback on the resource pack to inform ongoing improvements.
- Plan discussions about expanding the psychology team, including the potential addition of an assistant psychologist.
- Present the resource pack at the Trust planned care board and clinical standards group.

### Want to know more?

If you wish to know more about this project, please contact:

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